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ABSTRACT

The orientation and resources guide is intended for members of State Developmental Disabilities Councils to acquaint them with the problems and needs of hearing impaired developmentally disabled (HIDD) persons and with service models and resources that can be used to meet these problems and needs. The HIDD population is defined and described, and estimated prevalence figures for the nation and for each state are presented. Problems and needs of the HIDD population are reviewed, and the meaning of hearing loss is discussed in practical terms as well as in terms of educational, social, personal, and vocational adjustment. Six service models for the HIDD population are examined, and their strengths and weaknesses compared. Inter- and intra-agency coordination of services are considered, and several mechanisms available to foster coordination of services on behalf of HIDD persons are described. The State Developmental Disabilities Council's role in advocating improved services for HIDD persons is discussed, and possible ways that each state can conduct a needs assessment and plan services for this population are outlined. Also provided are listings of human and technical resources that can be used in service programing efforts, descriptions of training and technical services resources that can be tapped by the State Councils as needed, and a list of references. (DLS)

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HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS

AN ORIENTATION AND RESOURCES GUIDE FOR STATE DEVELOPMENTAL DISABILITIES COUNCILS

by

Larry G. Stewart, Ed.D.

THE MODEL DEMONSTRATION PROGRAM
THE REHABILITATION CENTER
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PREFACE

Developmentally disabled children and youth are slowly beginning to become recipients of necessary and appropriate educational and other human services, due to recent federal and state legislation, courtroom decisions, parental advocacy, and the organized efforts of the State Developmental Disabilities Councils.

Unfortunately, even with this new, enlightened tide sweeping across the land there is a significant minority group among the developmentally disabled that has remained largely unnoticed and underserved. This group—made up of persons who are developmentally disabled **and** also hearing impaired—is the subject of this publication.

Few advocates speak for the hearing impaired developmentally disabled population. Fewer still are the advocate **groups** whose members advocate for them.

State Developmental Disabilities Councils **can** become powerful advocates for this special, deserving group.

This book is dedicated to present and future members of the State Developmental Disabilities Councils with the hope that they will accept the challenge of Theodore Herzl:

Whoever would change men must change the condition of their lives.

Special thanks are due to the Federal Bureau of Developmental Disabilities, Rehabilitation Services Administration, Department of Health, Education and Welfare, for their sponsorship of the Model Demonstration Program. My personal thanks are here expressed to the staff members of the Model Demonstration Program who "toiled in the vineyard" with me to make this book possible. Most of all, grateful appreciation is extended to the many hearing impaired developmentally disabled children and adults, and their families and advocates, who taught us their needs.

The Author
Tucson, Arizona
November, 1978

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"Learn what is true in order to do what is right" is the summing up of the whole duty of man.

– T.H. Huxley

Chapter I

INTRODUCTION

This orientation and resources guide has been prepared especially for the members of each State Developmental Disabilities Council. It is intended to orient Council members to the problems and needs of developmentally disabled persons who have a hearing impairment, and also to acquaint Council members with service models and resources that can be used to meet these problems and needs.

The Need for This Guide

Hearing impairment is the leading disability in the United States. It affects more people than cancer, blindness, tuberculosis, venereal disease, multiple sclerosis, kidney disease, and heart disease combined. As many as fifteen million Americans may be afflicted by this disability at this time.

Ironically, despite its widespread prevalence, hearing impairment and its effects seem to be little understood by the American public. Loss of hearing brings with it no visible identifying characteristics. We may pass a hearing impaired person on the street without knowing it. We may even converse briefly with a hearing impaired person without detecting the existence of the impairment. Because some of the communication difficulties associated with hearing impairment are often present among other types of disabilities, we may even mistake hearing impairment for these other disabilities.

Hearing impairment may range from slight to severe in degree. Its onset may occur anytime from before birth to old age. The loss may be the only disability or it may be accompanied by one or more additional disabilities.

A hearing aid may or may not be helpful, depending upon the etiology of the disability as well as its nature and degree. Speech may or may not be affected, again depending upon age at onset, nature and degree, and other factors.

Special education provisions may or may not be indicated. A mainstreamed educational placement may be in order, or specialized residential school placement may be appropriate. The use of sign language could be essential, or only brief training in lip reading would be necessary.

The effects of hearing impairment on an individual's adult life adjustment and functioning may be minimal, or they may be pervasive and devastating. There are some profoundly deaf adults who are well adjusted and have careers in highly demanding professional areas. There are other adults who have only a mild hearing loss but because of the effects of their disability become totally dependent and withdraw from all competitive pursuits.

From this we can readily see that hearing impairment presents a complex picture for the American public. Even though it is the nation's most widespread disability, its generally invisible nature has resulted in a dearth of public awareness and understanding. Perhaps it is no small wonder that hearing loss has been referred to as America's silent, unseen epidemic.

The area of services and advocacy for persons who are developmentally disabled reflects this general lack of understanding of hearing loss and its implications. The legislation establishing the national program of services for the developmentally disabled – P.L. 91-517 – makes no special reference to hearing impairment among this population. Subsequent legislation – P.L. 94-103 – also fails to specifically mention hearing loss among the developmentally disabled.

This legislative oversight perpetuates a long standing history of national underservice to this special group of developmentally disabled persons. There have been sporadic, uneven attempts at selected locations to identify and meet the needs of hearing impaired developmentally disabled children and adults. However, in the face of the complexities of the needs of this multiply disabled, severely handicapped population, service personnel have lacked the expertise and the funding to mount significant comprehensive service program efforts.

Up to the present time, State Developmental Disabilities Councils also have tended to overlook hearing impairment among the developmentally disabled population. In setting priorities, in advocacy efforts, in preparing state plans – seldom has attention been given to the needs of these developmentally disabled persons with hearing impairment.

Service delivery systems for the developmentally disabled have tended to see hearing impairment as falling within the province of schools and agencies for the hearing impaired.

Conversely, service delivery systems for the hearing impaired have viewed the developmental disabilities as falling within the province of schools and agencies for the developmentally disabled.

Each type of system has too often assumed that the other was responsible for the hearing impaired developmentally disabled population. Unfortunately, as too often occurred, no one was serving this group.

The end product of this public and professional oversight in identifying and planning programming for the hearing impaired developmentally disabled population has been a waste of human resources as well as unnecessary suffering, loneliness, and isolation for the individual. Deinstitutionalization has largely been an empty promise for these children and adults.

This orientation and resources guide has been developed in a direct effort to bring the vast resources of State Developmental Disabilities Councils to bear upon the needs of hearing impaired developmentally disabled children and adults. The guide defines and describes the population and presents estimated prevalence figures for the nation and for each state.

The guide discusses the meaning of hearing loss in practical terms as well as in terms of educational, social, personal, and vocational adjustment. It presents descriptions of possible ways that each state can conduct a needs assessment and plan services for this population. There are listings of human resources and technical resources that can be used in service programming efforts. There is a description of training and technical services resources that can be tapped by the State Councils as needed. And finally, there is a list of references for State Council members who may wish to go into greater depth in learning about the hearing impaired developmentally disabled population.

This guidebook was prepared by the Model Demonstration Program for Hearing Impaired Developmentally Disabled Persons. The Model Demonstration Program is a three-year project of national significance funded by the Bureau of Developmental Disabilities, and U.S. Department of Health, Education and Welfare. The central purpose of the Model Demonstration Program is to develop descriptive models of services for hearing impaired developmentally disabled persons and disseminate these models nationally.

The State Developmental Disabilities Council is a key component in each state's effort to meet the needs of the developmentally disabled population. The Council and its members in all of the states are in a position to significantly remedy the current status of underservice to the hearing impaired developmentally disabled.

This is a tremendous responsibility. The job can and must be done.

The Model Demonstration Program offers this orientation and resources guidebook to State Council members as you begin to assist hearing impaired developmentally disabled persons to attain the rights guaranteed to them and to other developmentally disabled persons under P.L. 94-103.

The only good is knowledge, and the only evil is ignorance.

—Diogene Laertius

Chapter II

THE POPULATION

Who are the hearing impaired developmentally disabled?

Council members are familiar with the developmental disabilities. Hence, this chapte will focus upon the meaning of hearing impairment and the subpopulation of the developmentally disabled who also have a hearing loss.

Hearing impairment is not a single entity. Defining it clearly is difficult.

One way to look at hearing impairment is to consider what it is like to have a hearing loss.

Among other things, "hard of hearing" can mean

. . . understanding some people and not others.
. . . often saying, "Excuse me, what did you say?"
. . . straining to understand.
. . . just missing that important word that would make it all clear.
. . . wearing a hearing aid that clears up all the confusion.

or

. . . wearing a hearing aid that amplifies all sounds to the point where you want to scream.
. . . having well-meaning but unknowing people shout at you after they have noticed your hearing aid.

"Deafness" can mean

. . . the silent flowing and splashing of a towe ing waterfall.
. . . watching a glass shattering silently on a cement floor.
. . . the meaningless movements of a stranger's lips as he talks to you.
. . . endless hours in the public school classroom watching, uncomprehendingly, the teacher's mouth movements.
. . . the enlightenment that comes through sign language.
. . . the query of a kindly but unknowing stranger, "Oh, you are deaf. Do you read braille or have a seeing-eye dog?"

These are some aspects of the **real** meaning of hearing impairment. The examples tell us something of what it is like to **be** hearing impaired.

Definitions

It is important to have some insight into the experience of deafness. At the same time, it is useful to have operational definitions to help people communicate.

There are several operational definitions of hearing impairment and deafness. The variety of definitions may be confusing at first, but with growing familiarity with deafness, these variations can be easily perceived as different aspects of the disability.

Below, we shall present these definitions most applicable to education, habilitation, and rehabilitation.

a. **Educational Definition**

The Conference of Executives of American Schools for the Deaf presents the following definitions:

i. "**Hearing impairment**: A generic term indicating disability which may range in severity from mild to profound: it includes the subsets of **deaf** and **hard of hearing**.

ii. **A deaf person** is one whose hearing disability precludes successful processing of linguistic information through audition, with or without a hearing aid.

iii. **A hard of hearing person** is one who, generally with the use of a hearing aid, has residual hearing sufficient to enable successful processing of linguistic information through audition."

b. **Medical/Audiological Definition**

In their book, *Hearing and Deafness* (1978, p. 539), Davis and Silverman present the following definitions:

i. "**Hearing impairment**: This is the most general term for malfunction of the auditory mechanism. It does not distinguish either the anatomical area primarily involved (central vs. peripheral) or the functional nature of the impairment (sensitivity, frequency range, discrimination, sense of loudness or pitch, recognition of meaning, and the like). In a medicolegal context 'hearing impairment' implies a severity sufficient to 'affect personal efficiency in the activities of daily living,' specifically in respect to communication.

ii. **Deafness**: Deafness is the traditional term for a severe or complete loss of auditory sensitivity. For adults, it should only be used if the hearing threshold level for speech . . . is 93dB (ISO) or worse. This implies a hearing loss sufficient to make auditory communication difficult or impossible without amplification. For children, the cutoff level is often set as low as 70dB for educational purposes. . . . "

Table 1 presents a typical method of viewing the impact of hearing loss on speech comprehension, which is a basic frame of reference for viewing the meaning of hearing loss.

TABLE 1

CLASSES OF HEARING HANDICAP

Hearing Threshold Level dB (ISO)	Class	Degree of Handicap	Average Hearing Threshold Level for 500, 1000, and 2000 Hz in the Better Ear[a]		Ability to Understand Speech
			More Than	Not More Than	
	A	Not significant		25 dB (ISO)	No significant difficulty with faint speech
25	B	Slight handicap	25 dB (ISO)	40 dB	Difficulty only with faint speech
40	C	Mild handicap	40 dB	55 dB	Frequent difficulty with normal speech
55	D	Marked handicap	55 dB	70 dB	Frequent difficulty with loud speech
70	E	Severe handicap	70 dB	90 dB	Can understand only shouted or amplified speech
90	F	Extreme handicap	90 dB		Usually cannot understand even amplified speech

[a]Whenever the average for the poorer ear is 25 dB or more greater than that of the better ear in this frequency range, 5 dB is added to the average for the better ear. This adjusted average determines the degree and class of handicap. For example, if a person's average hearing-threshold level for 500, 1000, and 2000 Hz is 37 dB in one ear and 62 dB or more in the other his adjusted average hearing-threshold level is 42 dB and his handicap is Class C instead of Class B.

(From Davis & Silverman, 1977, p. 271.)

Hearing Impairment and the Developmental Disabilities

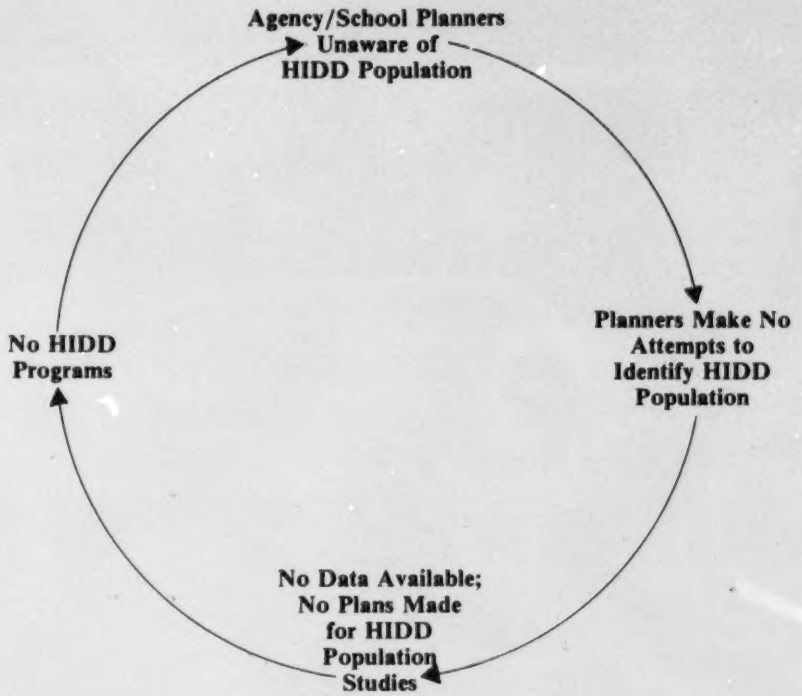
Despite the arbitrary schism between hearing loss and the developmental disabilities created by service programs founded upon categorical federal legislation, developmentally disabled children and adults do sometimes have a hearing impairment. Children and adults who are perceived primarily as hearing impaired do sometimes also have one or more of the developmental disabilities.

How widespread is hearing loss among those who are perceived as developmentally disabled?

How prevalent are the developmental disabilities among those who are perceived as hearing impaired?

Frankly, we do not know. There has never been a census addressing these two questions. Further, even if a census were conducted, there would be serious problems in identifying persons who have these multiple disabilities (hearing impairment **plus** one or more developmental disability). Our service systems and our schools in each state have yet to mount substantial efforts to do a thorough job of screening and identifying handicapped children and youths. As legislation and public awareness focus more clearly on the problems, gaps that have always existed in these areas are now "growing" wider, simply due to growing awareness.

Part of the problem at present is that agency and school program planners lack sufficient sensitivity to the fact that hearing impairment can be a serious problem among the developmentally disabled. Being thus unaware, human and financial resources are not channeled into refinements for improving identification and reporting on this population. This being the case, pertinent data are not collected. Having no data, planners remain unaware. A "cycle of inertia" is perpetuated.

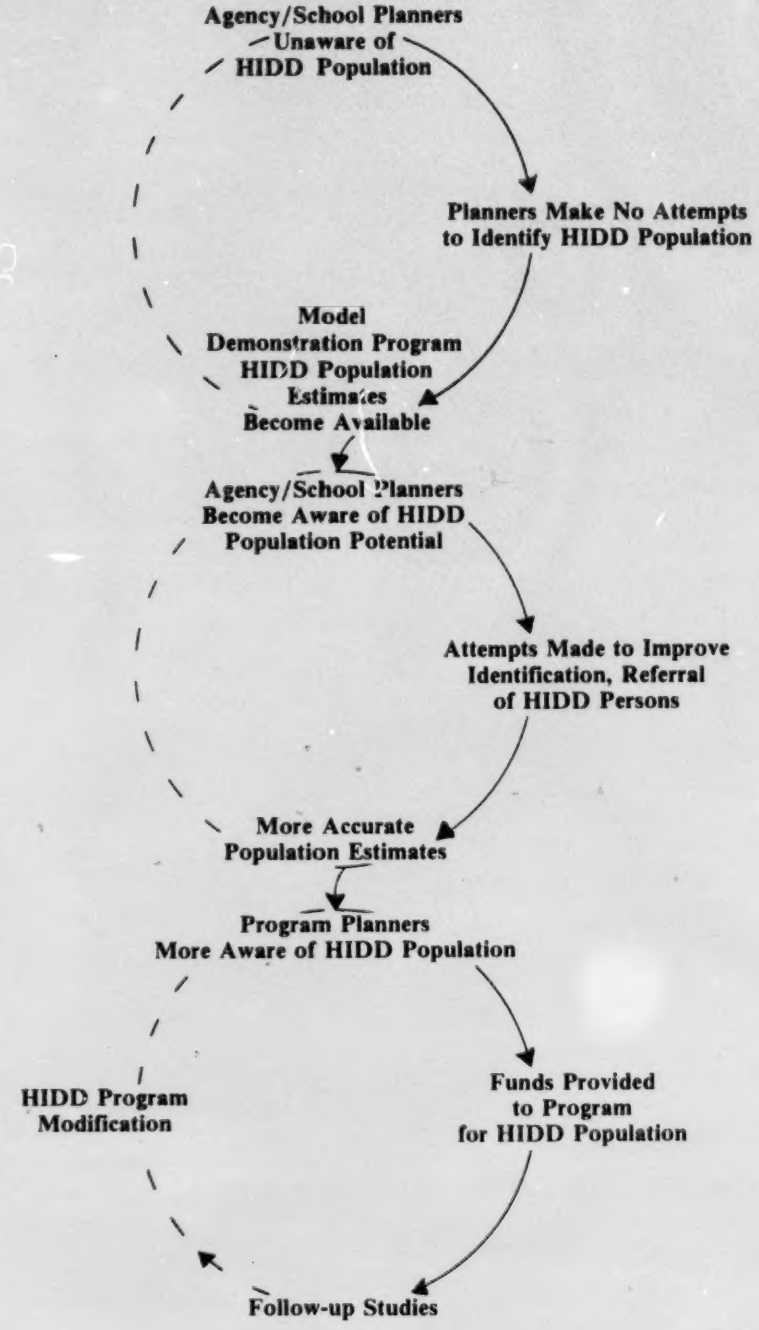

Agency/School Planners Unaware of HIDD Population
Planners Make No Attempts to Identify HIDD Population
No Data Available; No Plans Made for HIDD Population Studies
No HIDD Programs

CYCLE OF INERTIA

Breaking this cycle requires information on the hearing impaired developmentally disabled population. In the absence of highly accurate data, approximations and estimates must be made. Such estimates can then be used to break the cycle of inertia and create identification and reporting systems that produce more exact population demographic information. Agency planners can then plan services based upon real, identified needs.

We see, then, the basic need for initial estimates on the population of hearing impaired developmentally disabled persons. The following section represents an attempt to arrive at reasonably reliable and valid prevalence figures for the nation and for the individual states and territories.

CYCLES OF GROWING AWARENESS AND PROGRAM RESPONSE


Agency/School Planners Unaware of HIDD Population
Planners Make No Attempts to Identify HIDD Population
Model Demonstration Program HIDD Population Estimates Become Available
Agency/School Planners Become Aware of HIDD Population Potential
Attempts Made to Improve Identification, Referral of HIDD Persons
More Accurate Population Estimates
Program Planners More Aware of HIDD Population
Funds Provided to Program for HIDD Population
Follow-up Studies
HIDD Program Modification

Population Prevalence Estimates

As we know, the developmental disabilities as currently defined by federal law include autism, cerebral palsy, epilepsy, mental retardation, and other conditions closely related to mental retardation, which originate prior to a person's attainment of the age of 18 years, which have continued or can be expected to continue indefinitely, and constitute a substantial handicap to such persons' ability to function normally in society.

The hearing impaired developmentally disabled (HIDD) population consists of those persons who are developmentally disabled and also have a significant hearing loss. We shall first consider population prevalence rates for the developmentally disabled, then present estimates for the hearing impaired population, and thirdly, submit extrapolations based upon these data in an effort to arrive at a logical (if not precise) prevalence estimate for the HIDD population.

Developmental Disabilities. It has been estimated that approximately 3% to 6% of the U.S. population, or between 6 to 12.6 million people, have one or more of the developmental disabilities. The following section presents prevalence estimates for the four basic categories of the developmental disabilities.

1. **Autism.** Recent estimates of the prevalence of autism in the general population range from 4.3 per 10,000 (Brask, 1970) to 4.8 per 10,000 (Traffert, 1970; Wing, et al., 1976). Applying the higher rate to the January, 1977, population of the United States yields a current prevalence figure of 102,960 persons.

Discussing this prevalence rate, Cerva (1977, p. 13) comments:

> *Autism is described almost totally as a childhood disability. Most researchers use the term as connoting childhood autism although many children with autism reach adulthood with the same symptoms. These adults are likely to be labeled mentally retarded or mentally ill. This procedure by definition insures that the prevalence rate for autism is highest among children. There is also a historical problem here. Most of the work on autism has occurred in the last 25 years so that the oldest cohort of individuals who were correctly labeled autistic in childhood is now only 30 or 40 years old.*

2. **Cerebral Palsy.** According to a pamphlet distributed by the United Cerebral Palsy Association (1977) 750,000 children and adults in the U.S. have cerebral palsy, and more than 250,000 of them are under 21 years of age. Cerva (1977) quotes these figures, adding that his rate translates into a rate of .36% (.0036).

3. **Epilepsy.** Estimates of the prevalence of epilepsy in the U.S. population range from less than 1% to 5%. Basing its estimate upon nine studies, the Epilepsy Foundation of America (1975) states that epilepsy has a prevalence rate of 2% in the U.S. Applying this rate to the 1977 U.S. population suggests that there are currently 4,290,000 children and adults with epilepsy.

4. **Mental Retardation.** The American Association on Mental Deficiency has estimated that the prevalence rate for mental retardation is 3%. According to this estimate, then, the January, 1977, U.S. population of 214,500,000 included 6,435,000 mentally retarded persons.

5. **All Developmental Disabilities.** Combining the above population prevalence estimates for autism, cerebral palsy, epilepsy, and mental retardation results in an overall prevalence rate of

5.4% or a current total of 11,596,000 children and adults. However, many persons have more than one developmental disability, and consequently such persons are counted more than once in the preceding estimates. Cerva (1977) attempts to correct for such overlapping estimates by reducing the combined population prevalence rate to an even 5% for all developmental disabilities. This reduction, then, results in a current estimate of 10,725,000 for the developmentally disabled population in the U.S.

Hearing Impairment. The prevalence of hearing impairment in the U.S. has recently been studied extensively by the National Association of the Deaf and the Department of Health, Education and Welfare's Rehabilitation Services Administration (Schein & Delk, 1971). In this nationwide census of deaf people, the investigators reported the following information.

All Hearing Impairments. Concerning the prevalence and prevalence rates for hearing impairments in the civilian noninstitutionalized population, Schein and Delk (1971) reported 13,362,842 children and adults in the U.S. with some degree of hearing impairment. This represents a prevalence rate of 6,603 per 100,000, or 6.6%.

1. **Significant Bilateral Hearing Impairment**: This category encompasses hearing loss in both ears, with the individual having some difficulty hearing and understanding speech through the better ear (Schein & Delk 1971, p. 133). In this category, the investigators reported there were 6,548,242 persons of all ages, or a prevalence rate of 3,236 per 100,000. This represents 3.2% of the total population.

2. **Deafness**: In the deafness category ("inability to hear and understand speech") Schein and Delk (1971) reported a prevalence of 1,767,046 persons of all ages. This is a rate of 873 deaf persons per 100,000 population, or .873%.

(a.) **Prevocational Deafness**: Schein and Delk (1971) used the classification "prevocational deafness" to refer to all ages at onset of deafness up to 19 years. In this subgroup they represented 410,522 deaf persons, for a prevalence rate of 203 per 100,000 (.203%).

(b.) **Prelingual Deafness**: This category was used by the investigators to include all deaf persons who became deaf prior to three years of age. A prevalence of 201,626 persons was found in this category, which represents a prevalence rate of 100 per 100,000, or .1%.

In applying the 1971 prevalence rate to the 1977 U.S. population estimate of 214,500,000, the following prevalences should obtain (assuming 1971 rates remain valid for 1977):

Category	Prevalence Rate	1977 Population Estimate
All hearing impairment	6.6%	14,157,000
Significant Bilateral	3.2%	6,864,000
Deafness	.873	1,869,580
Prevocational	.203	435,435
Prelingual	.1	214,500

Hearing Impaired Developmentally Disabled. There have been no reported studies of the prevalence of hearing impairment in combination with the four developmental disabilities in the U.S. population. Even when hearing impairment and **one** of the developmental disabilities is considered, most related studies have been restricted in methodology. The problem seems to be essentially one of diagnosis and sampling. The hearing impaired/developmentally disabled (HIDD) population represents an especially hard-to-diagnose group. Superimposed on the communication problems inherent in developmental disabilities are the communication problems related to loss of hearing. Symptoms overlap among these classifications, and many developmentally disabled persons fail to respond to sophisticated audiometric assessment procedures. While evoked response audiometry represents a breakthrough in testing nonresponsive persons, the methodology currently is not readily available for widespread use due to manpower scarcity. The following information is presented with these limitations in mind.

1. **Hearing Impaired/Autistic:** There is currently very little information available on this population due to two problems. Differentiating autism *per se* from other diagnostic classifications presents one problem. Another problem is that autistic persons exhibit severe communication deficits that can be differentiated from the problems caused by hearing loss only by sophisticated audiometric procedures. These difficulties have up to now precluded reliable studies of the prevalence of HIA. However, if we assume that the prevalence rate of hearing impairment among the U.S. population is similar for autistic persons, then we may expect 6.6% (Schein & Delk, 1971) of autistic persons, who comprise 4.8% per 10,000 of the 1977 U.S. population of 214,500,000, to be hearing impaired.

$$(.066) \quad X \quad \left(\frac{4.8}{10{,}000}\right) \quad X \quad (214{,}500{,}000) \quad = \quad 6{,}795$$

Hearing Loss Rate		Autism Rate		U.S. Population (1977)		HIA Persons

Thus, of the estimated 102,960 autistic persons in the U.S., 6,795 may be hearing impaired.

2. **Hearing Impaired/Cerebral Palsied**: While the United Cerebral Palsy Association (1977) notes that cerebral palsy often is accompanied by hearing and/or speech problems, there is little information on the prevalence of hearing impairment among persons with cerebral palsy.

In the Schein & Delk (1971) census, .9% of the respondents reported having cerebral palsy. As will be seen below, this rate is more than double the prevalence rate for cerebral palsy among the hearing population (.36%).

The etiologies of cerebral palsy are often causative factors of hearing loss, and on this basis we may reasonably estimate that the prevalence of hearing loss is higher among the cerebral palsied than among the general population. The following estimate, then, should be viewed as a significantly low one.

$$(.066) \quad X \quad (.0036) \quad X \quad (214{,}500{,}000) \quad = \quad 50{,}965$$

Hearing Loss Rate		C.P. Rate		U.S. Population (1977)		HICP Persons

According to the above extrapolation, then, there were at least 50,965 hearing impaired cerebral palsied persons in the U.S. in January, 1977.

3. **Hearing Impaired/Epileptic Persons**: Hearing impairment among persons who are epileptic has not been studied to an appreciable extent due to the fact that the epileptic population itself has not been adequately studied in terms of numbers and other characteristics. In the absence of more definite information, then, the prevalence rate for hearing impairment among the general population may be applied to the epileptic population.

(.066)	X	(.02)	X	(214,500,000)	=	283,140
Hearing Loss Rate		Epilepsy Rate		U.S. Population		HIE Persons

Thus, among this country's 4,290,000 persons with some form of epilepsy, at least 283,140 have some degree of hearing loss. Since some of the etiologies of epilepsy also cause hearing loss, we may consider 283,140 to represent an underestimation.

4. **Hearing Impaired/Mentally Retarded Persons**: Hearing impairment among mentally retarded persons has been the subject of several recent studies.

According to Schein and Delk (1971, p. 123), 1.6% of the respondents surveyed in a national census of the deaf reported also having mental retardation. However, the Schein and Delk (1971) results came from a census of noninstitutionalized citizens; hence, the results are not applicable in considering the total HIMR population since so many of this population are in institutions.

The National Association of Superintendents of Public Residential Facilities for the Mentally Retarded (Scheerenberger, 1976, p. 14) reported that 2,806 or 2.8% of the 100,283 residents of public residential facilities for the mentally retarded were deaf and 1,600 (1.6%) were blind and deaf. However, the 237 public residential facilities reporting for the 1975-1976 year classified 74% of their residents as severely to profoundly retarded. In view of the difficulty inherent in audiological assessment of the severely and profoundly retarded, the validity of these reported data is questionable. For example, it was reported in 1961 that a mail survey indicated that the prevalence of hearing loss among the institutionalized retarded ranged from 0% to 50%. Rittmanic (1971), on the basis of a review of 27 surveys, also reported variation in reported prevalence of hearing loss, which ranged from 8% to 56%. Brannan, Sigelman, and Bensberg (1975) surveyed 212 state facilities for the mentally retarded, with 158 of these facilities returning more or less complete survey forms. Of these 158, 111 provided estimates of the hard-of-hearing and the deaf mentally retarded populations. There were 98,034 residents in these 111 institutions. Among these residents, 9,343 (9.54%) were reported as hearing impaired, or deaf; 7,100 (7.24%) were classified as hard of hearing; and, 2,243 (2.29%) were classified as deaf. However, estimates varied from institution to institution, with such estimates ranging from 0.21% to 35.4% for hard-of-hearing residents and 0% to 12.17% for deaf residents.

Although the Brannan *et al.* (1975) study represents one of the better studies in the field, the authors conclude:

> *However, the validity of these incidence figures was jeopardized by varying definitions of hearing impairment, approximate census figures, and incomplete survey data.*

Recent data generated by the UCLA-PSH Research Group covering 2,835 clients of the Inland Counties (California) Regional Center for the Mentally Retarded indicated that 243 clients were reported as having "some difficulty in hearing," "great difficulty in hearing," or "no hearing." The resulting prevalence rate of more than 8% for all hearing loss was below the rate of 14.7% (N = 251) reported for 1,700 residents of the Pacific State Hospital, Pomona, for the same time period.

Healey (1975) notes the wide range of prevalence estimates for the HIMR population, and suggests that a 10% rate may obtain. It is clear that previous studies have failed to result in a reliable prevalence rate estimate for the HIMR population. Considering the available data, two tentative rates may be considered pending further findings:

– Applying the 10% rate suggested by Healey (1975, p. 1) to the 1977 U.S. population of mentally retarded persons yields a current prevalence of 643,500 (6,435,000 x .10).

– Applying the 6.6% prevalence rate for hearing impairment (Schein & Delk, 1971) to the 1977 U.S. population of mentally retarded persons (6,435,000) results in a current prevalence of 424,611 HIMR persons.

In view of the fact that many of the causes of mental retardation also lead to hearing impairment, it is probable that the higher estimate (643,500) is closer to the true prevalence of hearing impairment and mental retardation.

5. **The HIDD Population**: The hearing impaired developmentally disabled population, according to the tentative estimates that have been derived from the above calculations, is composed of the following numbers on a national basis.

Hearing Impaired Autistic	6,795
Hearing Impaired Cerebral Palsy	50,965
Hearing Impaired Epileptic	283,140
Hearing Impaired Mentally Retarded	643,000
Hearing Impaired Developmentally Disabled	983,900

Many HIDD persons have more than one developmental disability, and the estimate of 983,900 may need to be corrected downward. However, it should be borne in mind that our population prevalence estimates must remain tentative until each state is able to carry out a more dependable count of its hearing impaired developmentally disabled population.

The following tables (2-12) offer a breakdown of estimated population prevalence figures for each of the 50 states as well as the Territories of Guam and Puerto Rico.

Please note that these figures are based upon 1970 U.S. census data rather than upon 1977 U.S. population estimates. This difference is occasioned by the fact that 1977 state-by-state estimates were not available at the time this publication was written. Thus, the data to follow do not match the preceding figures.

TABLE 2

ESTIMATED POPULATION PREVALENCE FIGURES FOR HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS OF ALL AGES IN D.D.O. REGION I 1970

D.D.O. Region/States	Population by 1970 U.S. Census	Hearing Impaired Autistic Population Estimate[1]	Hearing Impaired Cerebral Palsied Population Estimate[2]	Hearing Impaired Epileptic Population Estimate[3]	Hearing Impaired Mentally Retarded Population Estimate[4]	Hearing Impaired Developmentally Disabled Population Estimate[5]
Region I						
Connecticut	3,032,217	96	720	4,002	9,096	13,914
Maine	993,663	31	236	1,311	2,980	4,558
Massachusetts	5,689,170	180	1,351	7,509	17,067	26,107
New Hampshire	737,681	23	175	973	2,213	3,384
Rhode Island	949,723	30	225	1,253	2,849	4,357
Vermont	444,732	14	105	587	1,334	2,040
TOTALS	11,847,186	374	2,812	15,635	35,539	54,360

[1] Formula: .066 X .00048 X State Population (1970)
[2] Formula: .066 X .0036 X State Population (1970)
[3] Formula: .066 X .02 X State Population (1970)
[4] Formula: .10 X .03 X State Population (1970)
[5] Total HIDD Persons in Each State

TABLE 3

ESTIMATED POPULATION PREVALENCE FIGURES FOR HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS OF ALL AGES IN D.D.O. REGION II 1970

D.D.O. Region/States	Population by 1970 U.S. Census	Hearing Impaired Autistic Population Estimate[1]	Hearing Impaired Cerebral Palsied Population Estimate[2]	Hearing Impaired Epileptic Population Estimate[3]	Hearing Impaired Mentally Retarded Population Estimate[4]	Hearing Impaired Developmentally Disabled Population Estimate[5]
Region II						
New Jersey	7,168,164	227	1,703	9,461	21,504	32,895
New York	18,241,266	577	4,334	24,078	54,723	83,712
Puerto Rico	2,712,033	85	644	3,579	8,136	12,444
Virgin Islands	62,468	1	14	82	187	302
TOTALS	28,183,931	890	6,695	37,200	84,550	129,353

[1] Formula: .066 X .00048 X State Population (1970)
[2] Formula: .066 X .0036 X State Population (1970)
[3] Formula: .066 X .02 X State Population (1970)
[4] Formula: .10 X .03 X State Population (1970)
[5] Total HIDD Persons in Each State

TABLE 4

ESTIMATED POPULATION PREVALENCE FIGURES FOR HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS OF ALL AGES IN D.D.O. REGION III 1970

D.D.O. Region/States	Population by 1970 U.S. Census	Hearing Impaired Autistic Population Estimate[1]	Hearing Impaired Cerebral Palsied Population Estimate[2]	Hearing Impaired Epileptic Population Estimate[3]	Hearing Impaired Mentally Retarded Population Estimate[4]	Hearing Impaired Developmentally Disabled Population Estimate[5]
Region III						
Delaware	548,104	17	130	723	1,644	2,514
Washington, D.C.	756,510	23	179	998	2,269	3,469
Maryland	3,922,399	124	931	5,177	11,767	17,999
Pennsylvania	11,793,909	373	2,802	15,567	35,381	54,123
Virginia	4,648,494	147	1,104	6,136	13,945	21,332
West Virginia	1,744,237	55	414	2,302	5,232	8,003
TOTALS	23,413,653	739	5,560	30,903	70,238	107,440

[1] Formula: .066 X .00048 X State Population (1970)
[2] Formula: .066 X .0036 X State Population (1970)
[3] Formula: .066 X .02 X State Population (1970)
[4] Formula: .10 X .03 X State Population (1970)
[5] Total HIDD Persons in Each State

TABLE 5

ESTIMATED POPULATION PREVALENCE
FIGURES FOR HEARING IMPAIRED
DEVELOPMENTALLY DISABLED PERSONS
OF ALL AGES IN D.D.O. REGION IV
1970

D.D.O. Region/States	Population by 1970 U.S. Census	Hearing Impaired Autistic Population Estimate[1]	Hearing Impaired Cerebral Palsied Population Estimate[2]	Hearing Impaired Epileptic Population Estimate[3]	Hearing Impaired Mentally Retarded Population Estimate[4]	Hearing Impaired Developmentally Disabled Population Estimate[5]
Region IV						
Alabama	3,444,16[illegible]	109	818	4,546	10,332	15,805
Florida	6,789,443	215	1,613	8,962	20,368	31,158
Georgia	4,589,575	145	1,090	6,058	13,768	21,061
Kentucky	3,219,311	70	764	4,249	9,657	14,771
Mississippi	2,216,912	80	526	2,926	6,650	10,172
North Carolina	5,082,059	[illegible]30	1,207	6,708	15,246	23,321
South Carolina	2,590,516	82	615	3,419	7,771	11,887
Tennessee	3,924,164	124	932	5,179	11,772	18,007
TOTALS	31,856,145	1,006	7,565	42,047	95,564	146,182

[1] Formula: .066 X .00048 X State Population (1970)
[2] Formula: .066 X .0036 X State Population (1970)
[3] Formula: .066 X .02 X State Population (1970)
[4] Formula: .10 X .03 X State Population (1970)
[5] Total HIDD Persons in Each State

TABLE 6

ESTIMATED POPULATION PREVALENCE FIGURES FOR HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS OF ALL AGES IN D.D.O. REGION V 1970

D.D.O. Region/States	Population by 1970 U.S. Census	Hearing Impaired Autistic Population Estimate[1]	Hearing Impaired Cerebral Palsied Population Estimate[2]	Hearing Impaired Epileptic Population Estimate[3]	Hearing Impaired Mentally Retarded Population Estimate[4]	Hearing Impaired Developmentally Disabled Population Estimate[5]
Region V						
Illinois	11,113,976	352	2,640	14,670	33,341	51,003
Indiana	5,193,669	164	1,234	6,855	15,581	23,834
Michigan	8,875,083	281	2,108	11,715	26,625	40,729
Minnesota	3,805,069	120	904	5,022	11,415	17,461
Ohio	10,652,017	337	2,530	14,060	31,956	48,883
Wisconsin	4,417,933	139	1,049	5,831	13,253	20,272
TOTALS	44,057,747	1,393	10,465	58,153	132,171	202,182

[1] Formula: .066 X .00048 X State Population (1970)
[2] Formula: .066 X .0036 X State Population (1970)
[3] Formula: .066 X .02 X State Population (1970)
[4] Formula: .10 X .03 X State Population (1970)
[5] Total HIDD Persons in Each State

TABLE 7

ESTIMATED POPULATION PREVALENCE FIGURES FOR HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS OF ALL AGES IN D.D.O. REGION VI 1970

D.D.O. Region/States	Population by 1970 U.S. Census	Hearing Impaired Autistic Population Estimate[1]	Hearing Impaired Cerebral Palsied Population Estimate[2]	Hearing Impaired Epileptic Population Estimate[3]	Hearing Impaired Mentally Retarded Population Estimate[4]	Hearing Impaired Developmentally Disabled Population Estimate[5]
Region VI						
Arkansas	1,923,295	60	456	2,538	5,769	8,823
Louisiana	3,643,180	115	865	4,808	10,929	16,717
New Mexico	1,016,000	32	241	1,341	3,048	4,662
Oklahoma	2,559,253	81	608	3,378	7,677	11,744
Texas	11,196,730	354	2,660	14,779	33,590	51,383
TOTALS	20,338,458	642	4,830	26,844	61,013	93,329

[1] Formula: .066 X .00048 X State Population (1970)
[2] Formula: .066 X .0036 X State Population (1970)
[3] Formula: .066 X .02 X State Population (1970)
[4] Formula: .10 X .03 X State Population (1970)
[5] Total HIDD Persons in Each State

TABLE 8

ESTIMATED POPULATION PREVALENCE FIGURES FOR HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS OF ALL AGES IN D.D.O. REGION VII 1970

D.D.O. Region/States	Population by 1970 U.S. Census	Hearing Impaired Autistic Population Estimate[1]	Hearing Impaired Cerebral Palsied Population Estimate[2]	Hearing Impaired Epileptic Population Estimate[3]	Hearing Impaired Mentally Retarded Population Estimate[4]	Hearing Impaired Developmentally Disabled Population Estimate[5]
Region VII						
Iowa	2,825,041	89	671	3,729	8,475	12,964
Kansas	2,249,071	71	534	2,968	6,747	10,320
Missouri	4,677,399	148	1,111	6,174	14,032	21,465
Nebraska	1,483,791	47	352	1,958	4,451	6,808
TOTALS	11,235,302	355	2,668	14,829	33,705	51,557

[1] Formula: .066 X .00048 X State Population (1970)
[2] Formula: .066 X .0036 X State Population (1970)
[3] Formula: .066 X .02 X State Population (1970)
[4] Formula: .10 X .03 X State Population (1970)

[5] Total HIDD Persons in Each State

TABLE 9

ESTIMATED POPULATION PREVALENCE FIGURES FOR HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS OF ALL AGES IN D.D.O. REGION VIII 1970

D.D.O. Region/States	Population by 1970 U.S. Census	Hearing Impaired Autistic Population Estimate[1]	Hearing Impaired Cerebral Palsied Population Estimate[2]	Hearing Impaired Epileptic Population Estimate[3]	Hearing Impaired Mentally Retarded Population Estimate[4]	Hearing Impaired Developmentally Disabled Population Estimate[5]
Region VIII						
Colorado	2,207,259	69	524	2,913	6,621	10,127
Montana	694,409	21	164	916	2,083	3,184
North Dakota	617,761	19	146	815	1,853	2,833
South Dakota	666,257	21	158	879	1,998	3,056
Utah	1,059,273	33	251	1,398	3,177	4,859
Wyoming	332,416	10	78	438	997	1,523
TOTALS	5,577,375	173	1,321	7,359	16,729	25,582

[1] Formula: .066 X .00048 X State Population (1970)
[2] Formula: .066 X .0036 X State Population (1970)
[3] Formula: .066 X .02 X State Population (1970)
[4] Formula: .10 X .03 X State Population (1970)
[5] Total HIDD Persons in Each State

TABLE 10

ESTIMATED POPULATION PREVALENCE FIGURES FOR HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS OF ALL AGES IN D.D.O. REGION IX 1970

D.D.O. Region/States	Population by 1970 U.S. Census	Hearing Impaired Autistic Population Estimate[1]	Hearing Impaired Cerebral Palsied Population Estimate[2]	Hearing Impaired Epileptic Population Estimate[3]	Hearing Impaired Mentally Retarded Population Estimate[4]	Hearing Impaired Developmentally Disabled Population Estimate[5]
Region IX						
Arizona	1,772,482	56	421	2,339	5,317	8,133
California	19,953,134	632	4,740	26,338	59,859	91,569
Guam	84,996	2	20	112	254	388
Hawaii	769,913	24	182	1,016	2,309	3,531
Nevada	488,738	15	116	645	1,466	2,242
Trust Territory	90,940	2	21	120	272	441
TOTALS	23,160,203	731	5,500	30,570	69,477	106,304

[1] Formula: .066 X .00048 X State Population (1970)
[2] Formula: .066 X .0036 X State Population (1970)
[3] Formula: .066 X .02 X State Population (1970)
[4] Formula: .10 X .03 X State Population (1970)
[5] Total HIDD Persons in Each State

TABLE 11

ESTIMATED POPULATION PREVALENCE FIGURES FOR HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS OF ALL AGES IN D.D.O. REGION X 1970

D.D.O. Region/States	Population by 1970 U.S. Census	Hearing Impaired Autistic Population Estimate[1]	Hearing Impaired Cerebral Palsied Population Estimate[2]	Hearing Impaired Epileptic Population Estimate[3]	Hearing Impaired Mentally Retarded Population Estimate[4]	Hearing Impaired Developmentally Disabled Population Estimate[5]
Region X						
Alaska	302,173	9	71	398	906	1,384
Idaho	713,008	22	169	941	2,139	3,271
Oregon	2,091,385	66	496	2,760	6,274	9,596
Washington	3,409,169	108	810	4,500	10,227	15,645
TOTALS	6,515,735	205	1,546	8,599	19,546	29,896

[1] Formula: .066 X .00048 X State Population (1970)
[2] Formula: .066 X .0036 X State Population (1970)
[3] Formula: .066 X .02 X State Population (1970)
[4] Formula: .10 X .03 X State Population (1970)
[5] Total HIDD Persons in Each State

TABLE 12

ESTIMATED POPULATION PREVALENCE FIGURES FOR HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS OF ALL AGES IN ALL D.D.O. REGIONS 1970

D.D.O. Region/States	Population by 1970 U.S. Census	Hearing Impaired Autistic Population Estimate[1]	Hearing Impaired Cerebral Palsied Population Estimate[2]	Hearing Impaired Epileptic Population Estimate[3]	Hearing Impaired Mentally Retarded Population Estimate[4]	Hearing Impaired Developmentally Disabled Population Estimate[5]
Region I	11,847,186	374	2,812	15,635	35,539	54,360
Region II	28,183,931	890	6,695	37,200	84,550	129,353
Region III	23,413,653	739	5,560	30,903	70,238	107,440
Region IV	31,856,145	1,006	7,565	42,047	95,564	146,182
Region V	44,057,747	1,393	10,465	58,153	132,171	202,182
Region VI	20,338,458	642	4,830	26,844	61,013	93,329
Region VII	11,235,302	355	2,668	14,829	33,705	51,557
Region VIII	5,577,375	173	1,321	7,359	16,729	25,582
Region IX	23,160,203	731	5,500	30,570	69,477	106,304
Region X	6,515,735	205	1,546	8,599	19,546	29,896
ALL REGIONS	206,185,735	6,508	48,962	272,139	618,532	946,185

[1] Formula: .066 X .00048 X State Population (1970)
[2] Formula: .066 X .0036 X State Population (1970)
[3] Formula: .066 X .02 X State Population (1970)
[4] Formula: .10 X .03 X State Population (1970)
[5] Total HIDD Persons in Each State

Whoever would change men must change the conditions of their lives.

– Theodore Herzl

Chapter III

PROBLEMS AND NEEDS OF THE POPULATION

This chapter is about the developmental and adjustment problems and needs of children and adults who are multiply handicapped by one or more of the developmental disabilities **and** also a significant loss of hearing.

As we have seen, the hearing impaired developmentally disabled (HIDD) population is a **relatively large one.** It is also a **heterogeneous one.** *For any one category of the developmental disabilities, there are no less than 16 possible combinations of disability in reference to hearing loss.* Table 13 illustrates these possible combinations for autism. Parallel combinations are possible with cerebral palsy, epilepsy, and mental retardation. With 16 possible combinations for each of the four basic multiple disability categories (i.e., hearing loss and mental retardation, etc.), we see that there are 64 possible clear-cut combinations within the HIDD population.

The number of combinations possible where more than two disabilities are involved becomes staggering. We are faced with the fact that indeed a large proportion of HIDD persons **also** have a third and fourth disability if not even more. It is not uncommon for hearing impaired mentally retarded individuals to have some form of epilepsy, and cerebral palsy is often a fourth disability. Support for this statement can be found on an analysis of the characteristics of 249 children and adults served by the Model Demonstration Program in Arizona over an 18-month period of time in 1976, 1977, and 1978. The data demonstrated that almost 26% (64) of these 249 HIDD persons had three or more diagnosed disabilities.

Hence, it is clear that the HIDD population is made up of a wide variety of individuals having a broad, varied range of problems and needs. The complexities involved in understanding and serving the population can be bewildering if not overwhelming unless a meaningful perspective can be developed for viewing the population.

We propose that the factors of **communication ability and developmental lags** serve as the focal points in all considerations of the HIDD population and its problems and needs.

This is not to say that other problems of the population are secondary. Far from it. What we **are** saying is that HIDD people have problems that differ from other developmentally disabled persons because of their hearing loss and developmental lags. Hearing loss reduces auditory input from the environment and reduces if not eliminates auditory-based communication. The HIDD person is effectively put at a distance, or isolated from, the world of sound. From this comes a wide range of developmental problems and associated educational, social, vocational, and personal needs.

TABLE 13

16 Possible Combinations of Disabilities with Autism and Hearing Loss

Severity of Hearing Loss	Severity of Autism: Mild	Moderate	Severe	Profound
Mild	(1)	(2)	(3)	(4)
Moderate	(5)	(6)	(7)	(8)
Severe	(9)	(10)	(11)	(12)
Profound	(13)	(14)	(15)	(16)

The Problems of HIDD Persons

Infants who are born with a hearing loss are immediately faced with a course of development throughout their lives devoid of meaningful sound.

What are the implications of congenital hearing loss?

- Normal speech and language development is slowed if not practically stopped before a start can be made.
- Normal interpersonal communication within the family circle is limited if not completely precluded.
- Sound-based information from the environment does not reach the mind of the child, or it arrives in a distorted fashion. Warning sounds, familiar sounds, sounds that orient, sounds that help us learn and share, sounds that please and stimulate are absent or only vaguely received.
- Upon arriving at school age, the child enters first grade with no language patterns, little if any speech, and practically no form of meaningful communication. Many pieces of information the hearing child absorbs from birth until the age of six have not been assimilated by the hearing impaired child, and yet he or she is now expected to function and learn along with the hearing child.
- As the congenitally deaf child progresses through school, the gap between potential and achievement continuously widens. The older one becomes, the more important verbal language and verbal communication become. Yet, verbal communication and language are the deaf child's greatest weaknesses.

– The negative impact on subsequent learning and adjustment in adulthood is predictable unless appropriate special education efforts have been instigated at an early age.

These same implications are largely true for the child who becomes hearing impaired before the age of four or five years. This child and the congenitally hearing impaired child – both prelingually deaf – share common problems and needs.

The child who becomes hearing impaired after the age of four or five years (after the establishment of basic language skills and speech patterns) is not usually as severely handicapped as the congenitally or prelingually deaf child. Yet, other problems are presented when the input of sound is diminished or lost. A tool for survival (hearing) is taken away or weakened. Uncertainty occurs. Established ways of relating to others are disrupted. Speech usually deteriorates with the passing years. New input from the environment is distorted or lost. Functioning in the family, in the neighborhood, at school, and at play is impaired. A handicap is produced that will send echoes through the remainder of the child's life. Future educational growth, postsecondary education, career choices, social opportunities – all are affected.

The young adult is also uniquely affected by the onset and continuation of hearing loss. Although the individual may previously have developed normally within his or her capacities to do so, the onset of hearing loss initiates a major change in one's world. It is as if a curtain of silence, or a muffler of sorts, were placed between the individual and **everything else of an auditory nature**.

The same curtain of silence or muffled sound may descend upon the mature adult or older adult. In each case, a major tool for survival – hearing – is taken away or weakened. One's long-standing ways of communicating with the world are suddenly seriously impeded or destroyed. Painful readjustments must be made. One's psychological equilibrium may be thrown off center.

We can easily see that the effects of hearing loss are determined in large part by the type and severity of the loss as well as the age at onset of the loss.

Equally important factors to be considered are the extent and quality of family interaction with the hearing impaired person, early identification and treatment (medical, audiological), and appropriate social/educational/habilitation/rehabilitation services.

– The more family members interact constructively with the hearing impaired person, the better growth and development will be.

– The earlier the loss is identified, the earlier appropriate services and assistance can be rendered.

– The more appropriate the treatment (surgery, family or individual counseling and guidance, fitting with a hearing aid, speech therapy, instruction in sign language, appropriate educational placement, habilitation and/or rehabilitation services) at the earliest possible time, the less will be the impact of the hearing loss on one's development and adjustment.

Hearing loss may affect persons who are developmentally disabled in essentially the same manner that it affects nondevelopmentally disabled individuals, with one very important difference. *This difference, simply stated, is that hearing loss in a developmentally disabled person compounds the problems created by the developmental disability or disabilities.*

The autistic individual's adjustment is qualitatively affected by hearing loss. We as diagnosticians and treatment personnel often find it difficult to ascertain whether specific behavior is a function of hearing loss or autism, and the already-difficult task of interpersonal communication may become seemingly impossible.

The cerebral palsied individual's development and adjustment are obviously made more complicated by the language, speech, and communication handicaps imposed by hearing loss.

The person who is epileptic is adversely affected by hearing loss. Emotional frustrations increase as a consequence of the many problems created by each of these disabilities. The total impact upon the individual can have devastating effects in personal, social, and vocational areas.

The condition of mental retardation can only be worsened by any additional disability. Hearing loss in particular, because it creates a communication barrier between the person and his/her world, reduces input from the environment, and further complicates the mentally retarded person's developmental tasks.

Problems in the Services Area

The problems created by hearing loss, as we have seen, may present severe disruptions in one's growth and development. Unfortunately these problems, too often, go unheeded or untreated by workers in the human services fields.

- All too often, there are minimal attempts at early identification of developmentally disabled persons who have a hearing loss.

- Too few agencies or schools have personnel who are capable of diagnosing hearing loss among the more severely handicapped developmentally disabled population.

- Very few schools and facility programs have treatment/education/habilitation programs geared toward meeting the special needs of its developmentally disabled clients/students who are hearing impaired.

- Too many school and agency personnel, lacking a qualitative understanding of deafness, believe that a hearing aid and speech therapy are panaceas for all the problems of HIDD persons.

- Generally, too many program administrators assume that HIDD clients/students are benefiting from various services that "do not seem to require communication."

- Where sign language is used by program personnel, too often their expertise in the actual use of sign language is minimal. Program administrators, not knowing sign language, often assume a level of expertise in their staff that may not exist.

- There are explicit professional standards in the education of the deaf. There are explicit professional standards in the education of developmentally disabled persons.

  There are no established professional standards whatsoever in the education of hearing impaired developmentally disabled persons.

In this vacuum created by the lack of trained personnel and organized service program efforts, HIDD persons of all ages remain one of the most underserved minorities in the nation.

Service Needs of HIDD Persons

Considering the known problems of children and adults who are hearing impaired and developmentally disabled, what can we identify as their service needs?

The HIDD individual may need a program of specific services, depending upon the nature and severity of his or her handicaps. General needs of HIDD persons as a group, however, can also be identified. Each of these general needs may be seen as coming from the communication deficits and development lags associated with hearing loss. This statement, of course, acknowledges that the population also shares the problems and needs of other developmentally disabled persons. The task becomes one of removing, alleviating, or otherwise compensating for the deficits created by hearing loss within the framework of services for the developmentally disabled.

1. **Early Identification.** All HIDD persons need to be identified as early as possible after the onset of their hearing loss. The earlier the identification, the better.

2. **Referral.** HIDD persons and their parents need to be referred for appropriate assistance as soon as possible after identification.

3. **Direct Services.** Appropriate services are needed in a variety of locations and settings. The following listing of services gives an indication of the needed array.

In the state of Arizona (and Arizona is typical of other states in this regard) the Model Demonstration Program identified the following service needs of HIDD persons:

1. Prevention Programs
2. Early Identification
3. Appropriate Diagnosis
4. Proper Placement
5. Proper Instruction and Training
6. Parental Counseling and Guidance
7. Personnel Preparation
8. Sheltered Employment Opportunities
9. Pre-Vocational Training Opportunities
10. Vocational Training Opportunities
11. Group Living Opportunities
12. Independent Living Opportunities
13. Health Care
14. Recreational and Social Participation Opportunities
15. Community Support Services

As we can see, these services do not differ from those typically required for many developmentally disabled persons. **What is significant is that the great majority of these services are not readily available to or do not impact upon hearing impaired developmentally disabled persons because of the fact that few provisions are available for dealing with the client or student's communication problems.**

The situation amounts to a barrier to the delivery of available services; the barrier is hearing loss.

Many service workers tend to overlook the crucial nature of communication in the learning and adjustment process. They reason, "The service **is** here. If we expose the HIDD person, he or she will learn."

This view is a naive one. It is equivalent to offering these services to English-speaking clients through personnel who use a language such as Swahili or classical Sanskrit. Yes, eventually **something** will "soak in." The question is, "**Is this** how we want to do it?"

The use of Total Communication is crucial with seriously hearing impaired persons. Total Communication (TC) includes the simultaneous use of spoken language, sign language, gestures, and other visible communication devices and methods as well as auditory amplification when appropriate.

Moreover, an understanding of the nature of communication deficits as well as their impact on the individual is vital to the service worker. This knowledge enables the worker to concentrate service efforts upon activities that offer the most promise to HIDD individuals.

Through TC and proper understanding of the client's problems and needs, services in a variety of settings can successfully be provided to HIDD individuals.

Unfortunately, extremely few of Arizona's or the nation's service and education workers are well-versed regarding HIDD conditions and possess skill in the use of Total Communication.

Thus, "available" services are seldom actually available to many HIDD children and adults. Such clients are frequently not even diagnosed as such since many of them represent a hard-to-test group. In such cases, it becomes difficult to even imagine their receiving proper referral, let alone services.

Some HIDD persons can be effectively served by general community agencies and schools; as pointed out above, such agencies and schools need personnel who understand the problems and needs of this population and have the expertise necessary to meet these needs.

Some HIDD persons, because of the severity of their problems, cannot be served by most community agencies and schools. They need specialized assistance, perhaps within a regular school and agency, that can only be given by personnel highly trained to work with this population.

Some HIDD persons can only be served appropriately in a facility program designed for the developmentally disabled population and having program components designed specifically for meeting the needs created by hearing impairment.

Table 14 lists the types of hearing loss and their educational implications.

Table 15 lists the categories of mental retardation and some of their educational implications.

Combining the information from the two tables suggests implications for hearing impaired persons who are mentally retarded.

These examples provide a paradigm, even if less than a perfect one, for viewing the other developmental disability categories. By viewing the needs of the developmentally disabled along with

the needs created by hearing impairment we may arrive at a reasonable approximation of the needs of the hearing impaired developmentally disabled.

Thus, we may expect an ideal array of services for the HIDD population to consist of those services typically provided to the developmentally disabled **plus** special personnel and educational/training methodology and materials appropriate for dealing with the problems of hearing loss and associated developmental lags.

Tables 16, 17, and 18 present illustrations of this synergistic concept.

TABLE 14

HEARING LEVELS FOR SPEECH AND EDUCATIONAL RECOMMENDATIONS

Class	Hearing Level for Speech	Educational Recommendation
1	*30 dB or better.* These children may have difficulty in hearing faint or distant speech but are likely to "get along" in school and to have normal speech.	Children should be given the benefit of favorable seating in regular classrooms and may be assisted by special instruction in speechreading.
2	*30–55 dB* These children usually understand conversational speech at a distance of 3 to 5 feet without great difficulty. They may have some defects in the articulation of their own speech, and they may have difficulty in hearing adequately in school if the talker's voice is faint or if his face is not visible to them.	Children should wear hearing aids and be given training in their use. They should be taught speechreading and also be given the benefit of speech correction and conservation of speech. They should also have the advantage of favorable seating in classrooms.
3	*55–70 dB* These children understand conversational speech only if it is loud, and they have considerable difficulty in group and classroom discussions. Their language and especially their vocabularies may be limited, and abnormalities of articulation and voice production are obvious.	Hearing aids and auditory training, special training in speech, and special lnaguage work are all essential. With such assistance and with favorable seating, some children can continue in regular classes. Others may derive more benefit from special classes.
4	*70–90 dB* These children may hear the sound of a loud voice about one foot from the ear, and they may identify some environmental noises and may distinguish vowels, but even with hearing aids they have difficulty with consonants. The quality of their voices is not entirely normal, and they must be taught both speech and language. Many, but not all, children in this class should be considered "deaf" for educational purposes until or unless the combination of an adequate hearing aid and sufficient auditory training makes them only "hard of hearing."	Children should be taught by means of educational procedures for the deaf child, with special emphasis on speech, on auditory training, and on language. After a period of such instruction it is possible that these children may enter classes in regular schools.
5	*90 dB or worse* These children are deaf, even though they may hear some very loud sounds. They never can rely on the auditory channel as a primary avenue of communication. Their speech and their language must both be developed through careful and extensive training.	These children require special educational procedures described in this chapter. Some of them, however, eventually enter high schools for the hearing.

(Davis & Silverman, 1977, p. 436)

TABLE 15

LEVELS OF MENTAL RETARDATION AND THEIR EDUCATIONAL IMPLICATIONS

Mental Retardation Level	Program Needed
1. Mild	Usually can function adequately in most general programs in public schools with resource help.
2. Moderate	Usually can function well in public school with special instruction.
3. Severe	Can sometimes function in public school special programs; often individualized training (beyond group instruction). Sometimes require special facility placement for training purposes.
4. Profound	Usually require special training and care. Some are well served in the community. Individualized attention needed.

TABLE 16

COMBINING EDUCATIONAL SERVICES FOR THE DEVELOPMENTALLY DISABLED AND FOR THE HEARING IMPAIRED

Service Location	Population	Program Modification
1. Public School Classes (Mainstreaming)	A. Appropriate D.D. population with mild hearing impairment	A. Appropriate seating B. Possible student use of hearing aid C. Speech therapy D. Orientation of teachers to hearing impairment E. Use of visually oriented media
	B. Appropriate D.D. population with moderate hearing impairment	A. Modifications similar to those for "Mild" hearing plus B. Use of resource teachers and ancillary professionals
2. Classes in Schools for the Deaf	A. HIDD persons with mild to moderate D.D. involvement and severe to profound hearing loss	A. Use of hearing aids B. Use of group hearing aids C. Use of sign language D. Special training in language, speech, academic areas
3. Special Classes in Public Schools	A. HIDD persons with moderate to severe HI and D.D. involvement	A. Special instruction B. Use of hearing aids and group hearing aids C. Heavy visual orientation D. Use of sign language as well as speech
4. Residential Facility	A. Severe to profound D.D. involvement, mild degree of hearing loss	A. Use of hearing aid B. Speech therapy C. Orientation of staff to hearing loss D. Use of visually oriented media
	B. Severe to profound D.D. involvement, moderate hearing loss	A. Use of modifications for moderate degree of loss B. Use of resource staff specializing with HIDD population
	C. Severe to profound D.D. involvement, severe to profound hearing loss	A. Use of hearing aids B. Special staff C. Special grouping for instructional purposes D. Use of sign language

TABLE 17

COMBINING COMMUNITY RESIDENTIAL SERVICES FOR THE DEVELOPMENTALLY DISABLED AND FOR THE HEARING IMPAIRED

Service Location	Population	Program Modifications
1. Residential Housing (Community-based)	A. D.D. individuals who have a mild hearing impairment	A. Orientation of housing staff to hearing impairment B. Client use of hearing aid C. Appropriate seating
	B. D.D. individuals who have a moderate hearing impairment	A. Orientation of staff to hearing impairment B. Client use of hearing aid C. Visual fire alarms D. Resource staff
	C. D.D. individuals who have a severe to profound hearing loss	A. Orientation of staff to hearing impairment B. Client use of hearing aid as appropriate C. Specialized staff to work with clients D. Client-staff use of sign language E. Visual fire alarms F. Specialized instruction

TABLE 18

COMBINING COMMUNITY COUNSELING AND REFERRAL SERVICES FOR THE DEVELOPMENTALLY DISABLED AND FOR THE HEARING IMPAIRED

Service Location	Population Served	Program Modifications for HIDD Persons
1. Community Counseling Centers	A. General Population	A. Orientation of staff to HIDD persons B. Use of interpreters for deaf D.D. clients
2. Community Counseling Centers for the D.D. population	A. General D.D. population	A. Orientation of staff to HIDD persons and resources B. Use of interpreters for HIDD clients or employment of staff skilled in sign language
3. Community Counseling Centers for the Deaf	A. General hearing impaired population	A. Orientation of staff to HIDD population and resources related to the D.D.

You cannot choose your battlefield
The gods do that for you,
But you can plant a standard
where a standard never flew.
– Nathalia Crane

Chapter IV

SERVICE MODELS

There are several distinct service models, or approaches, available to program planners who desire to plan appropriate services for developmentally disabled persons who are also hearing impaired. These models are described in this chapter, and brief, general criteria are presented to serve as guidelines for selecting a particular model.

Introductory Background

Our country's educational and human services systems have traditionally offered a variety of approaches to meeting the developmental and adjustment needs of all its citizens, young and old. Initially, our approach was a general one. We had one-room schoolhouses with one teacher for a heterogeneous group of children of varied ages. There were family doctors who took care of everyone, and dealt with all kinds of maladies. We had general stores that provided everything from buttons to plowshares, medicine, wagons, and meat. Gradually, however, specialization has developed and we are now a nation of specialists and specialties. Yet, we continue to see some trends back toward a generalist point of view in many different fields. Hence, in many areas of life there are options whereby we may select a general type of program activity or benefit, or we may select highly specialized ones. The choice is mediated by real needs, personal preferences, availability, and financial as well as professional trends in a given locality. Political forces also play a role.

Thus it is with hearing impaired developmentally disabled persons. Although comparatively little in the services arena has evolved specifically for HIDD persons, it is clear that there **are** options available to program planners who wish to initiate a focus upon meeting the needs of this population.

Planners have the following options:

Option I: **The Generic Model**: Absorb HIDD persons into general human services agencies or public schools, and depend upon the generalist's knowiedges and skills to meet student/client needs.

Option II: **Semi-Specialized Model A**: Provide generalists with special information about the HIDD population, and expect this to be adequate preparation for the generalist to meet the needs of this group.

Option III: **Semi-Specialized Model B**: Use **Option II** above, but additionally employ one specialist with HIDD persons to provide "resource information" to both the

generalist staff and to the client or student. Such a resource person is often called a coordinator or consultant, and this individual is expected to be able to resolve any special problems encountered by the general staff with HIDD persons.

Option IV: **Specialized Model A**: Use **Option III** above plus additionally employ one or more specialists (a sign language teacher, a psychologist, a counselor, a special teacher, etc.) to provide "remedial" or "special support" services as a back-up for regular services.

Option V: **Specialized Model B**: Employ a specialist staff to work exclusively with HIDD persons in a special unit within a general facility or school or agency.

Option VI: **Special Facility Model**: Employ a specialist staff to work exclusively with HIDD persons in a special facility serving **only** HIDD persons.

Strengths and Weaknesses of Options

Each option or model has its advantages and disadvantages, its benefits and its shortcomings, its adherents and its opponents. It is unfortunate but true that all too often the actual model selected in a given state or city is more a function of agency personalities and personal priorities than of deliberate, carefully thought-out analysis and planning. The analysis offered below is an attempt to illustrate a rational analysis of each model's strengths and weaknesses. This information has potential value for agency planners.

Generic Model

Strengths: The generic model requires no extra funding, personnel, or organizational adaptations.

Weaknesses: Does not permit real focus upon special needs or the delivery of expert, specialized service approaches.

Semi-Specialized Model A

Strengths: Same as Generic Model, but adds a degree of special knowledge and skill to worker qualifications.

Weaknesses: Same as Generic Model, and further encourages stereotyping unless training offers specific **caveats**.

Semi-Specialized Model B

Strengths: Similar to Semi-Specialized Model A, but increases worker knowledges and skills through consultation.

Weaknesses: Similar to Generic Model, but not as great.

Specialized Model A

Strengths: Provides generic benefits plus specialized benefits.

Weaknesses: Resource assistance may be inadequate for the more severely handicapped, who may require extensive, intensive services over a long period of time.

Specialized Model B

Strengths: Offers generic benefits along with the benefits of specialized, extensive and intensive services.

Weaknesses: Conflict may occur between the generic staff and the specialized staff over space, funds, scheduling, rules and regulations, staff salaries, philosophy, service approaches, program organization.

Special Facility Model

Strengths: Highly specialized services can be offered to students or clients on an extensive, intensive, long-term basis. Removes bureaucratic conflict with generic staff.

Weaknesses: This model requires a very high initial cost for facilities and staff; reduces opportunities for client/student interaction with other people in social settings (unless programming includes opportunities for same); requires recruitment of a special staff.

The Generic Model (Option I) can truly "work" (i.e., be effective) only with the very mildly impaired HIDD client or student. The Semi-Specialized Models A and B offer benefits primarily with the mildly impaired. The Specialized Models A and B offer substantial benefits to HIDD clients/students, and the Special Facility Model (Option VI) offers extensive benefits in special areas (e.g., education, vocational training, residential living, etc.).

Advocates and program planners ought to bear in mind that any one state can expect to have a variety of schools and agencies serving HIDD clients, with these schools and agencies offering a mixture of "Models." Hence, long-range planning will recognize the desirability of fostering a chain of varied service options rather than one single option in one single location.

We are born for cooperation,
as are the feet, the hands,
the eyelids, and the upper and
lower jaws.
— Marcus Aurelius Antoninus

Chapter V

COORDINATION - A PROBLEM AND A CHALLENGE

A persistent, nagging problem in the delivery of human services is that of poor or mediocre coordination of services. We all know of myriad instances of duplication of effort, of clients being "dropped between the cracks" in the identification and referral process, and of frustrating delays as the client moves "between" agencies. Indeed, the Rand Corporation, and the General Services Administration (GSA) of the federal government, have identified "poor coordination of available services" as THE major barrier to the effective delivery of human services. This problem appears to be especially severe with the mentally ill and the developmentally disabled who, because of the seriousness of their needs, often cannot effectively advocate for their own rights or get through the red tape so frequently associated with applying for assistance.

This problem of inadequate coordination of services is especially severe for HIDD clients/students, and in fact poor coordination of services for this group may be viewed as the epitome of agency service coordination problems in the U.S. Although, by law, both services for the deaf and services for the developmentally disabled **should** be available to HIDD persons, it is far too often the case that each service group assumes the other group is the major resource for this population. That this assumption exists partially reflects the fact of poor coordination of efforts, for if these schools and agencies truly communicated and coordinated their efforts they would know their present assumptions are invalid.

The Problem

There are two basic types of coordination in the human services area. One is interagency coordination, and the other is intra-agency coordination.

1. **Interagency Coordination.** In this type of coordination, means and processes of interaction between two or more agencies are effected to facilitate the delivery of appropriate and timely client/student services **by each agency**.

When these means and processes are not specificied and monitored, coordination becomes incoordination. The resources of each agency are weakened due to delays, conflicts, omissions, and untimely commissions. The client/student "bounces from pillar to post," waiting, often in vain, for the appropriate services at the appropriate time.

2. **Intra-agency Coordination.** Even small, two- or three-person agencies may fall victim to problems with coordination. Incorrect assumptions may be made about the who, what, when, how, and where of client services. Poor communication, inexperience, lack of knowledge, and the absence of planning may foster incoordination whenever as few as two people work together. This being the case, the likelihood of poor coordination increases with the number of personnel involved and the complexity of the task. Hence, poor coordination occurs not only **between** agencies but **within** agencies. And, the larger the agency the greater is the possibility for intra-agency incoordination.

Again, only deliberate planning and clearcut lines of responsibility, coupled with careful monitoring of results, can eliminate the inefficiency and even active harm that stems from poorly coordinated service delivery efforts.

The Challenge

The coordination of services for HIDD persons requires that "fixing" of responsibility for services at all levels–local, countywide, statewide. Accountability must be defined and monitored.

The question of "who insures coordination" on behalf of HIDD persons within given service systems (education, rehabilitation, etc.) represents the basic issue here. **Unless this question is answered, coordination will not occur.**

Several mechanisms are available to foster coordination of efforts on behalf of HIDD persons.

1. **Interagency Coordinating Council.** A special statewide committee may be established by concerned schools and agencies for the specific purpose of fostering communication, client/student referrals, and exchange of information as well as long-range planning activities. One individual from each concerned agency can serve as a member of the committee. Typical agencies/schools to be represented on this committee might be:

- School(s) for the hearing impaired
- School(s) for the developmentally disabled
- Community agencies serving the hearing impaired, the developmentally disabled, or both groups
- Vocational rehabilitation agencies
- Post secondary education facilities serving hearing impaired and/or developmentally disabled people
- Health planning agencies
- The State Department of Education
- The State Developmental Disabilities Department
- The State D.D. Council

A monthly or bimonthly meeting of such a statewide council can do a very great deal to foster effective interagency coordination and cooperation.

2. **Statewide Coordination of Services for HIDD Persons.** A second potentially effective mechanism for fostering improved interagency coordination of services is the appointment of one individual to serve as a "Statewide Coordinator of Services for HIDD Persons." Although such a person would be limited in terms of authority due to his/her placement within one department of state services, his/her advocacy efforts need not be stifled.

The coordinator position might be located within a super agency and be one duty of a present staff member or be the single role of a new or existing staff member.

This approach would permit an ongoing effort on a broad scale on behalf of HIDD persons, and would counter current trends that result in small minority groups being overlooked for lack of ongoing advocacy.

3. **State D.D. Council Subcommittee.** A third, useful option available to the states is for the State D.D. Council to establish a subcommittee from among its members, charging the subcommittee with the task of maintaining up-to-date information on services for HIDD persons. The resulting information could be periodically shared with service providers via a newsletter. Also, subcommittee meetings could be held with appropriate agency representatives invited to attend and give presentations. This process would do much to foster greater coordination.

4. **Other Options.** No state is exactly like any other state in terms of agency organization, personnel, funding availability, interest, and political dynamics. The three options described above do not exhaust available concepts for improving coordinating efforts on behalf of HIDD persons. New, unique approaches are encouraged and should be sought, ranging from advocacy groups to citizen's information centers. The actual delivery of timely, appropriate services to HIDD persons is a goal; the "How" of achieving this goal must be an individual, state-by-state decision. The decision, however, is overdue; action is needed **now**.

Intra-agency coordination involves issues and problems similar to those discussed for interagency coordination. Committee and coordinators are encouraged within agencies to bridge the gap that so often develops between and among other departments within one agency.

The course of human history is determined not by what happens in the skies but by what takes place in the hearts of men.

– Sir Arthur Keith

Chapter VI

THE STATE DEVELOPMENTAL DISABILITIES COUNCIL: HOPE FOR THE FUTURE

Thus far, we have drawn a picture of hearing impaired, developmentally disabled persons that includes the following features:

- The population is significantly large.
- The population has serious problems and needs that are special due to communication problems and related developmental lags.
- Few special, widescale efforts have been made to meet the special needs of this population in a comprehensive manner.
- Special knowledges and techniques exist for meeting the needs of HIDD persons, but these are not widely known.
- There is little advocacy on behalf of HIDD persons.
- The lack of coordination of services has serious negative effects on the delivery of services to HIDD persons. Means exist to remedy this problem.
- The "How" of improving services for HIDD persons must be determined by the individual states.

The question thus presents itself: "Who should advocate for improved services for HIDD persons in your state?"

The answer to this question is clear. Under P.L. 94-103, the State Developmental Disabilities Council has the responsibility to fulfill a planning and advocacy role for **all** developmentally disabled persons. The fact that a developmentally disabled person is also hearing impaired should not serve to discourage Council interest. On the contrary, because hearing impairment creates further barriers to the delivery of services, the State Council might well view the needs of this population as a special challenge in the planning and advocacy area.

The fact, as we have seen, is that relatively few agency heads are truly familiar with the broad ramifications of hearing loss. Very few citizen advocates serve as sentinels for the rights of HIDD people. Few institutional facilities have mounted comprehensive service program for HIDD people.

There are many fine public programs for hearing impaired people who do **not** have developmental disabilities. We cannot say the same for hearing impaired people who **do** have one or more of the developmental disabilities. In fact, our nation's past and present neglect of HIDD persons is a disgrace.

A change is needed. It is needed **now**.

This change must be initiated by a group with legislated authority to advocate for change.

This group is the State Developmental Disabilities Council.

Need for Information

In a recent publication, a task force under the Secretary of the U.S. Department of Health, Education and Welfare identified three major reasons for the mediocre services provided to HIDD persons. These were:

- Lack of information (on HIDD persons)
- Lack of Resources
- Lack of Coordination

Education and service agencies lack information concerning the HIDD population. They need this information before they can design proper programs.

The State Council can help to disseminate this information.

Need for Advocacy

HIDD persons are a minority group. They have few advocates, and even fewer **influential** advocates.

HIDD persons can rarely speak for themselves. They need others to speak for them. They need for others to learn of their problems, needs, and potentials.

The State Council can serve as an influential advocate for HIDD persons.

Need for Short- and Long-Range Planning

Agency and school planners are generally unaware of HIDD persons, and do not usually consider them when designing short- or long-range plans for services.

HIDD persons need to be considered when short- and long-range plans are made by state agencies.

The State D.D. Council can insure that HIDD persons are given fair consideration whenever state agencies meet to plan for the future.

The State D.D. Council can serve as a model for other state organizations and agencies by including HIDD persons in the Statewide Plan of the Council.

However, in the end the State D.D. Council will need to involve other schools and agencies that have a legislated or vested interest in the HIDD population. A "needs assessment" can be an appropriate vehicle for initiating the organized involvement of these schools and agencies.

We will either find a way or make one.

– Hannibal

Chapter VII

CONDUCTING A NEEDS ASSESSMENT

Background

The successful development and implementation of any type of human service on an organized basis requires, above all else, adequate funding along with initial acceptance and support from other agencies. Achieving these "ingredients," in turn, is contingent in large measure upon clearly communicating the need for new services and how this need can be met in an operational manner.

Interestingly, the impetus for innovative services seems to originate only occasionally **within** a service system or bureaucracy. Rather, citizen advocates, the legislative process, or the courts are most often the primary stimuli for program growth and innovative activities. This phenomenon appears to be especially prevalent where minority groups such as the handicapped are concerned.

The "How Do You Know?" Syndrome

All too often, the citizen, or professional from outside the service system who is advocating new services, encounters skepticism from service agency heads and legislators. It is common for these leaders to greet proposals for new services with the following responses (in one form or another), which we may call the "How Do You Know?" syndrome:

1. How many people are in the group of children and/or adults that will benefit from this proposed service? How do you know?

2. Where are they? How do you know?

3. What are their problems? How do you know?

4. Why aren't existing services filling this need? How do you know?

5. How can these people be helped? How do you know?

We might justifiably ask why agency heads and legislators themselves do not have the answers to these questions since they are, after all, supposed to be "leaders" and supposedly aware of the needs of the citizens in the state. It would seem much more appropriate for the legislator and agency leader to supply answers to these questions rather than to put the onus for doing so upon the citizen or professional who lacks the time and resources to hunt up all these answers!

Unfortunately, it does sometimes happen that the citizen advocate and members of advocacy groups may find themselves on the receiving end of tough questions that must be answered before new services can be funded and implemented. And, answers must be substantiated in a reasonable manner by as many facts as can be assembled. A **needs assessment**, if carefully conducted, can often mean the difference between success and failure in convincing legislators and administrative skeptics of the need for new services and how these can be initiated.

Initiating a Needs Assessment

In today's grant-oriented society it is almost axiomatic that a "needs assessment" must be conducted in order to justify **any** program modification or new programmatic effort. The concept of justifying the expenditure of public funds and the manner in which funds are expended appears to be commendable. In actual practice, however, it often turns out that the process of justifying new programs becomes so complex and technical that the citizen advocate often stands no chance against intrenched professional grantsmen. The latter, from long experience, usually know the key "jackpot" words that attract funds, and they are paid to spend time processing application forms, keeping up to date on "facts," monitoring reports, and preparing budgets. The Title XX (Social Security) morass is but one example of roadblocks that frustrate citizen advocates and drain off creative energies.

Despite the existence of these and other inhibitors to citizen advocacy, it **is** still possible for the astute advocate to gather information in the form of facts and opinions that can be used to catalyze the development of necessary services for handicapped persons. This chapter provides information for that purpose on behalf of hearing impaired developmentally disabled persons.

A needs assessment might consist of a statement of population characteristics, population estimates, problems, needs, and recommendations.

1. **Population Definition**. One of the first questions the advocate for HIDD persons is asked is, "Who are you talking about?" Chapters I and II supply answers for this question.

2. **Population Size**. The second question often asked by the legislator or agency head is, "How many people are you talking about?" Again, Chapter II answers this question.

Many skeptics will challenge the figures in Chapter II on the grounds that the data are simply statistical estimates based upon statistical estimates, and hence unreliable. In response, the advocate would be justified in arguing that (a) state agencies and schools use similar statistical estimates to justify **their** budgets and activities, so why not the advocate? (b) the estimates in Chapter II are conservative; and (c) state agencies cannot give an any more reliable estimate because they have never, up to now, looked closely at the HIDD population as a group. Hence, why not accept the estimate in Chapter II, since it is a reasonable one, until a better job can be done at the state level?

It will not be uncommon for the legislator or administrator to respond with population figures that indicate a substantially smaller population than is suggested by Chapter II data. These figures will usually come from **known** cases of hearing impaired developmentally disabled cases (i.e., those known to agencies). A review of Chapters I-III will clearly indicate the fact that HIDD conditions are very difficult to report upon accurately, hence **known cases do not represent all actual cases.**

3. **Population Problems, Needs**. Chapters III and IV provide information that can be used to answer questions about population problems and needs. This is general information, however, which

should be substantiated by a statewide needs assessment of available problems of, and resources for HIDD persons. In other words, the problems and needs will vary in magnitude from state to state.

At the end of this chapter are two typical needs assessment questionnaires that can be used with agency workers, parents of HIDD persons, and citizen advocates. Unfortunately, invalid results may be obtained from respondents who are not familiar with the facts, and for this reason the questionnaire should be used only with people who are in a position to provide reliable information.

Another aspect of the two questionnaires is that certain respondents may indicate that "special services" are offered when only generic services are available. In Arizona in 1976, for example, an overwhelming majority of general agency respondents to the questionnaire viewed services for HIDD persons as "adequate," whereas specialists who directly work with this population (e.g., counselors, teachers, program coordinators) as well as parents viewed HIDD services as "inadequate."

The questionnaires, it should be noted, are quite detailed. Briefer versions can be developed for acquiring more general information. However, when the time comes to justify requests for new programs it is better to have very specific information for agency heads and/or legislators. The results of a carefully detailed and analyzed needs assessment can offer compelling information in favor of new program efforts.

NEEDS ASSESSMENT
FORMS

PART I (To be completed by agency/school program directors)

HEARING IMPAIRED DEVELOPMENTALLY DISABLED PERSONS

Service Program Questionnaire

NAME OF INTERVIEWER: _____ Date of Interview: _____

Agency Contact Person: _____ Title: _____

1. Name of agency: _____
2. Address of agency: _____ Zip Code: _____
3. Telephone number(s): _____
4. Chief Administrator: _____
5. Agency is supported by: _____

   _____ State _____ City _____ County _____ Other (Specify: _____)
6. Annual Budget: _____
7. Check (✓) to indicate services your agency offers:

	Pre School			School Age			Adult				Cost to Client
	HI	DD	HIDD	HI	DD	HIDD	HI	DD	HIDD	Category	
A.										Information and referral	
B.										Audiological screening	
C.										Audiological assessment (in-depth)	
D.										Speech and hearing services	
E.										Manual communication instruction	
F.										Medical assessment	
G.										Medical treatment (Nature: _____)	
H.										Educational assessment	
I.										Psychological assessment	
J.										Counseling	
K.										Parent education	
L.										Parent counseling	
M.										Occupational therapy	
N.										Physical therapy	
O.										Recreation	
P.										Personal care	
Q.										Transportation	
R.										Activities of daily living	
S.										Residential living	
T.										Supervised community living	
U.										Day care	
V.										Education	
W.										Training	
X.										Vocational training	
Y.										Sheltered workshop	
Z.										Protective/Legal	

PART II (To be completed by personnel serving HIDD individuals, and also by parent advocates)

NEEDS ASSESSMENT – HIDD

Name of Respondent _____

A. Population Identification

1. Identify, by age period, present organized efforts in (state) to identify hearing impaired developmentally disabled persons.

Ages Served	Agency(ies)	Nature of Effort
A. **0-5**		
1)		
2)		
3)		
4)		
B. **6-12**		
1)		
2)		
3)		
4)		
C. **13-18**		
1)		
2)		
3)		
4)		
D. **19 and over**		
1)		
2)		
3)		
4)		

PART II

NEEDS ASSESSMENT – HIDD (Continued)

Name of Respondent_____

B. Programs for HIDD Persons

1. Identify the programs (i.e., organized efforts) that presently provide meaningful services to HIDD persons.

PROGRAM NAME ADDRESS	AGES SERVED	NATURE OF SERVICES
A.		
B.		
C.		
D.		
E.		
F.		
G.		
H.		
I.		
J.		

PART II
NEEDS ASSESSMENT – HIDD (Continued)

Name of Respondent _____

City of Residence _____

C. Services for HIDD Persons

Directions: Review the list of services below, then indicate, using the code below, your assessment of current services availability, quality, and need. Write down "DK" if you are unable to make a valid assessment in any category.

Code: 1 = Adequate; 2 = Available, but needs improvement; 3 = serious need; 4 = don't know (DK)

SERVICES	AGE GROUP			
A. Diagnostic	**0-5**	**6-12**	**13-18**	**19 & over**
1. General Medical Assessment				
2. Otological				
3. Ophthalmological				
4. Audiological				
5. Psychological				
6. Psychiatric				
7. Neurological				
8. Educational				
9. Social Work				
10. Vocational Evaluation	N/A	N/A		
11. Other (Specify:)				
12. Other (Specify:)				
B. Education/Training/Residence				
1. Parent Information				
2. Parent Education				
3. Parent Therapy/Counseling				
4. Speech Therapy				
5. Use of Hearing Aid				
6. Manual Communication				
7. Physical Therapy				
8. Specialized Nursing Care				
9. Preschool Education		N/A	N/A	N/A
10. Public School Programs				
11. Special Residential School Programs				
12. Custodial Residence Programs				
13. Special Day Care Programs				
14 Curriculum Guides				
15. Instructional Materials				

HI DD

PART II
NEEDS ASSESSMENT – HIDD (Continued)

Name of Respondent_____

D. Prevention

1. Identify below present efforts now being made in the area of prevention of disabling conditions that create the multiple disability of hearing impairment and developmental disabilities.

	Effort	Sponsoring Agency	Area Served
a.			
b.			
c.			
d.			

2. List below the needs that are important but not now being met uniformly specifically to prevent the combined disabilities referred to by the term "hearing impairment and developmental disabilities."

	Prevention Effort	Potential Program Sponsor	Potential Source of Funds
a.			
b.			
c.			
d.			

3. Rank order the needs listed above in No. 2 according to importance.

PART II
NEEDS ASSESSMENT – HIDD (Continued)

Name of Respondent _____

E. Professional Training

1. Identify present efforts that are being made to provide professional training for personnel to meet the needs of HIDD persons. Disregard commonly known efforts.

Nature of Training	Discipline	Degree or Non-Degree	Location	HIDD Age Group Affected

2. Identify present needs that exist for training personnel to serve HIDD persons.

   a. **Short Term (Workshop, In-Service, etc.) Needs**

	Disciplines	Nature of Training	Potential Sponsors	Potential Locations	Potential Funding Source
1)					
2)					
3)					
4)					

PART II
NEEDS ASSESSMENT - HIDD (Continued)

Name of Respondent _____

F. Research

1. Identify present efforts that are under way that are highly relevant to meeting the needs of HIDD persons. While many research efforts relate to such needs, our interest is in those that relate directly to the HIDD population.

Nature of Research	Sponsor	Location	Age Group Affected

PART II
NEEDS ASSESSMENT – HIDD (Continued)

Name of Respondent _____

G. Instructional Technology

1. Identify those instructional and other service technologies that are now available to or that may be acquired for/applied with, HIDD persons. Consider curricula guides, specialized teaching materials and equipment, and the like.

Nature of Technology	Source of Technology	Age Group for Which Intended

PART II
NEEDS ASSESSMENT – HIDD (Continued)

Name of Respondent _____

H. Health Concerns

1. Identify specialized health care agencies and resources that are specifically available for HIDD populations. Disregard those agencies and resources that are commonly known.

Agency/Resource	Nature of Services	Age Group Served

PART II
NEEDS ASSESSMENT – HIDD (Continued)

Name of Respondent _____

I. Facilities

1. List the facilities in (state) that are known to provide **specialized** services to HIDD persons.

Name of Facility	Location	Population Served	Nature of Facilities

If you're not part of the solution, you're part of the problem.
– Eldridge Cleaver

Chapter VIII

HUMAN AND TECHNICAL RESOURCES

Initiating new, innovative service programming efforts on behalf of the severely handicapped is, as we have seen, fraught with complex difficulties and continuing frustrations. The temptation to give up, to rationalize our failures, and to blame "the system" or personalities is great. Yet, to paraphrase Eldridge Cleaver,

If you're not part of the solution, you're part of the problem.

With the special complexities involved in mounting and sustaining activities to improve services for hearing impaired developmentally disabled persons, however, it becomes crucial that all available human and technical resources be available to those who wish to participate in the solution. Such resources can go a long way toward bringing order and meaning to an often disorganized or overlapping service area.

Unfortunately, at this point in time there are very few state or national training/technical assistance services oriented toward the problems and needs of HIDD persons. For this reason, it is especially important that the resources that do exist be made known to State D.D. Council members. Council members, in turn, may share this information with others.

1. National Resources

a. The Model Demonstration Program

At present there is only one national resource specifically focusing upon the HIDD population. This resource is the Model Demonstration Program for Hearing Impaired Developmentally Disabled Persons. The Bureau of Developmental Disabilities, Rehabilitation Services Administration, funded the Model Demonstration Program in October of 1976 as a three-year project of national significance. The purpose of the project is to conduct research, demonstrations, and professional training activities, and to develop service products designed to advance the state of the art in serving HIDD children and adults.

At present the Model Demonstration Program offers the following types of assistance:

1) **Training**. The Model Demonstration Program periodically sponsors training workshops on selected topics relevant to HIDD services and program development. One of two current 1978-79 priorities is sponsoring statewide workshops designed to bring workers from various disciplines together to mount a statewide effort to improve services for HIDD persons. However, other types of workshops with more specific service orientation (audiology, rehabilitation, educational curricula, etc.) can be arranged.

The second 1978-79 priority is orientation of State D.D. Council members to the HIDD population and its needs.

2) **Technical Assistance.** The Model Demonstration Program offers the expertise of its professional staff members to programs desiring consultation in such areas as audiology, curriculum, counseling, psychology, instructional media, program analysis, program development, personnel competencies, residential and transitional living, communications, and staff development. Such consultation may be arranged on an individual basis.

The Model Demonstration Program is currently contracting with a limited number of schools and agencies throughout the nation to conduct a comprehensive, in-depth analysis of organizational capabilities in serving HIDD students/clients. These analyses are designed to provide agency heads with information for their own use in considering future program planning for HIDD persons.

3) **Products.** The Model Demonstration Program has developed a variety of instructional and informational media to be used for staff in-service training, client/student services, public information, and program design. Most of these are available at no cost, while certain media such as videotapes are offered at cost.

Examples of products available to State D.D. Council members include, but are not limited to, the following:

Printed Products

- *Annotated Bibliography of Resource Materials for Use in Teaching the Hearing Impaired Developmentally Disabled*
- *Audiology with Hearing Impaired Developmentally Disabled Persons: An Annotated Bibliography*
- *Counseling Families of the Hearing Impaired Developmentally Disabled Person: An Annotated Bibliography*
- *Counseling Hearing Impaired Developmentally Disabled Persons: An Annotated Bibliography*
- *Education Programs for Hearing Impaired Developmentally Disabled Persons: Design and Administration*
- *Educational Services for the Hearing Impaired Developmentally Disabled: A Review of Programs at the State Department of Education Level*
- *Hearing Impaired Developmentally Disabled Persons in the United States: Definitions, Causes, Effects and Prevalence Estimates*
- *A Preliminary Survey of Services Available to HIDD Students in Residential Schools for Hearing Impaired Students*
- *Residential Facility Programs for the Hearing Impaired Developmentally Disabled: The ATPC Sensory Training Unit Model*
- *Severely Handicapped Deaf People: A Perspective for Program Administrators and Planners*
- *Legal and Constitutional Rights of Hearing Impaired Developmentally Disabled Children and Adults*
- *Vocational Programming and Evaluation for Hearing Impaired Developmentally Disabled Persons: An Annotated Bibliography*

Non-Print Media

- *Total Communication for Workers with HIDD Persons: An Instructional Videotape Series*
- Other Training Tapes

For an up-to-date listing, contact the Model Demonstration Program.

b. **Gallaudet College.** Gallaudet College is the world's only liberal arts college for the deaf. It offers both undergraduate and graduate level studies as well as a Public Services program designed to offer assistance to the community in the area of deafness.

For further information, contact:

Public Services Office
Gallaudet College
Florida Avenue at 7th St., N.E.
Washington, D.C. 20002

c. **National Technical Institute for the Deaf.** NTID offers special education and training for the deaf, and as such is a repository of specialized information on deafness and employment as well as specialized instructional technology.

For further information, contact:

National Technical Institute for the Deaf
1 Lomb Memorial Drive
Rochester, New York 14623

d. **National Associations.** There are many national associations offering information on hearing impairment and deafness. Included among them are:

American Deafness and Rehabilitation Association, Inc.
814 Thayer Avenue
Silver Spring, Maryland 20910

Alexander Graham Bell Association for the Deaf, Inc.
3417 Volta Place, N.W.
Washington, D.C. 20007

National Association of the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910
(Plus, each state has a state association of the deaf, usually affiliated with the N.A.D.)

Registry of Interpreters for the Deaf
P.O. Box 1339
Washington, D.C. 20013

National Association of Parents of the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910

National Center for Law and the Handicapped
1235 N. Eddy St.
South Bend, Indiana 46617

2. **State Level Resources**

Each state usually has several resources for the hearing impaired. Examples are:

- Within the State Department of Education there is a Special Education Department usually employing one or more specialists in the area of deafness.
- Each state has one or more state schools for the deaf.
- Many school districts operate a special program for the deaf within the public school system.
- Each state's Vocational Rehabilitation Agency employs one or more special counselors for the deaf; some employ a Statewide Coordinator of Services for the Deaf.
- Some states have a special Commission or Council for the Deaf, with a staff of one or more individuals providing special technical and/or consultation services to other agencies and communities.

3. **Local Resources**

The larger cities in the U.S. have clubs and other organizations made up of deaf persons. Usually these groups are organized for social and recreational purposes. Many churches offer special services for deaf persons.

Some cities have a special community service agency for the deaf.

Most states have a state chapter of the Registry of Interpreters for the Deaf, with members in most of the larger cities.

4. **A Special Note on Interpreting Services.**

Traditionally, deaf people have been neglected in the courts and by service providers in that few attempts were made to provide interpreters for them at official trials, hearings, conferences, and the like.

Today, the right of the deaf person to have appropriate interpreting services in certain situations is recognized as a basic legal and constitutional right.

HIDD persons facing court competency hearings and/or other legal proceedings are entitled by law to appropriate interpreting services.

Consequently, the development of a community's pool of qualified interpreters for the deaf should be viewed as a priority activity. Moreover, not everyone who can use sign language is

qualified to serve as an interpreter. Only properly qualified interpreters should be employed. Certification as an interpreter for the deaf by the Registry of Interpreters for the Deaf is one means of assessing an interpreter's qualifications.

5. **Federal Resources**

The following Federal resources can offer important assistance to advocacy groups interested in HIDD and other deaf groups.

a. Bureau of Developmental Disabilities
Rehabilitation Services Administration
Office of Human Development
Department of Health, Education and Welfare
Washington, D.C.

b. Bureau of Education for the Handicapped
U.S. Office of Education
Department of Health, Education and Welfare
400 Maryland Ave., S.W.
Washington, D.C. 20202

c. Office of Deafness and Communicative Disorders
Rehabilitation Service Administration
Department of Health, Education and Welfare
Washington, D.C. 20201

Advocates desiring more detailed information concerning resources for the hearing impaired should subscribe to the following:

Directory of Programs and Services
American Annals of the Deaf
5034 Wisconsin Avenue, N.W.
Washington, D.C. 20016

To everything there is a season, and a time to every purpose under the heaven.
Ecclesiastes

Chapter IX

THE FUTURE

Where do the State Developmental Disabilities Councils go from here in their advocacy activities for and on behalf of hearing impaired developmentally disabled persons?

This book has attempted to describe the HIDD population as well as its problems and needs. Information has been presented on activities that can be undertaken to deal with these problems and needs. Human and technical resources have been listed for those desiring to make use of them. Needs assessment forms are waiting to be used.

Recently Dr. Samuel Kirk, a pioneer in the field of mental retardation, commented:

> *The Model Demonstration Program should have happened 20 years ago. There has been no improvement for HIDD persons in two decades.*

Dr. Kirk's comments serve to emphasize this great need for advocacy on behalf of HIDD persons.

We hope **your** response will be vigorous and positive. Looking to the future, 20 years from now let's be able to say that hearing impaired developmentally disabled individuals finally became a priority in the human services field in the 1970's, and the State Developmental Disabilities Councils made it happen.

Good luck. Call on the Model Demonstration Program for help. We're ready when you are.

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